The Future of Glaucoma: Essential Themes from the Patient Perspective

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INTRODUCTION

- The management of patients with glaucoma is undergoing significant transformation, driven by the increased use of virtual and technician-led clinics, allied health professionals, and emerging technologies. As services evolve, it is crucial to understand how these changes are perceived and experienced by patients.
- The *Future of Glaucoma* is an initiative designed to explore and curate the themes and trends shaping the next chapter of glaucoma care. By incorporating crowd-sourced insights from both clinicians and patients, the project aims to identify opportunities for improvement and innovation in care delivery—both in the UK and globally.
- In alignment with NHS Constitution Principle 4, the initiative places patients at the heart of its vision. To that end, this research set out to better understand the patient perspective on the future of glaucoma care, exploring what patients value most, where they see opportunities for change, and how care can be made more inclusive, clear, and supportive.

METHODS

STUDY DESIGN

Focus groups and one-to-one interviews were conducted with patients in October 2024, recruited through a range of channels, including from databases of patients who have expressed an interest in participating in healthcare research, via social media channels and healthcare forums. Recruitment aimed to ensure a diverse spectrum of demographics, disease progression, severity, and patient expertise, with a focus on non-expert patients.

INCLUSION CRITERIA

All participants had a confirmed diagnosis of glaucoma and were selected to reflect a mix of treatment centres, socioeconomic backgrounds, genders, and durations since diagnosis. Additionally, at least two participants per group had prior experience with glaucoma surgery.

DATA ANALYSIS

The study employed an Interpretative Phenomenological Analysis approach to explore patient experiences, identify common themes, and examine differences across age groups and ethnic backgrounds. Three age-adjusted focus groups (90 minutes each) were conducted to ensure that insights unique to specific life phases were captured, alongside eight individual in-depth interviews (60 minutes) specifically targeting patients from high-risk ethnic backgrounds.

TABLE 1. BASELINE DEMOGRAPHICS AND CHARACTERISTICS

Patients, n	Age 35-50 years (n=8)	Age 50-65 years (n=9)	Age 65+ years (n=9)	Total (n=26)
Focus group participants	6	6	6	18
One-to-one interviews				
Afro-Caribbean patients	1	1	2	4
Asian patients	1	1	1	3
White patients	0	1	0	1

KEY THEMES: PRIORITIES TO ENSURE POSITIVE CARE EXPERIENCES

1. ACCURATE, TARGETED TESTING

Even if they are from high-risk groups, patients may not get tested for glaucoma on a regular basis because they are unaware of their individual risk; this is especially true in younger patients.

- Patients spoke of the need for an emphasis on regular testing, particularly for those at higher risk of sight loss.
- Targeted messaging and public facing awareness campaigns are crucial to engage high-risk groups (e.g., specific ethnicities, family history).

"I didn't get an eye check for 5-6 years. I thought I can see alright, I was so busy with my business at the time, and I thought 'if it's not damaged, why fix it?'. The guy at the clinic asked me why I didn't get it checked earlier."





"I went online and checked it out because at the clinic they didn't even tell me what glaucoma meant and what the long-term effects of it was, what I could be facing in a few years' time."

2. CONFIDENCE IN THE TESTING PROCESS

Patients need to feel reassured that their condition will be picked up during the testing process and they get clarity around their diagnosis, especially during the initial consultation.

- Patients want reassurance that the system will definitely 'catch them' at the right time.
- Trust in the accuracy of their diagnosis and more personalized advice.
- Time to ask questions and clarity on individual circumstances are essential for building confidence.

3. PATIENT-FRIENDLY COMMUNICATION

Patients may have little knowledge about glaucoma when they receive their diagnosis. Understanding of the condition empowers them to ask questions and process what it means for them.

- Clear, jargon-free explanations about glaucoma and treatments (e.g., eye drops) are vital.
- Patients value accessible information in non-written formats to support their daily lives.

"There was just a big assumption that I knew what glaucoma was, I knew what it was all about, I knew how it might progress and what was going to happen."





"I know what I need to focus on for now, but I have no idea what I may be facing a few years down the line. I would feel much more reassured if I knew that there were other treatment options for me in the future"

4. KNOWING THE AVAILABLE OPTIONS

Discussing potential future treatment options drives engagement and reduces anxiety.

- Patients seek empowerment through joint decision-making and clear explanations of treatment options (surgical and non-surgical) throughout their disease management, not only at the point of making decisions.
- Anxiety can be alleviated by discussing future possibilities and providing a rationale for current and potential treatments.
- Sign posting to information or role models can help patients inform themselves.

5. JOINED-UP CARE

Patients may experience aspects of care via a variety of providers. Effective collaboration between care providers is crucial to a positive patient experience.

- Patients want clarity on care pathways and roles within the multidisciplinary team.
- Effective communication between stakeholders (e.g., optometrists, GPs, specialists) to avoid repetition and ensure seamless care and appropriate recommendation of treatments.

"Get the basics right – it may be that I'm being sent here and there for optimal care, but I need to know that, and want to feel that it is joined up"





"If I start to get worried between visits, I do pop down to a high street optometrist for a pressure check"

6. OWNERSHIP

Patients may feel safer when they see the same healthcare provider on a regular basis with whom they can build trust and a rapport. Patients want clarity on who has clinical ownership of their care.

- They also seek tools and information to self-advocate and manage their condition outside clinical touchpoints, with the knowledge that they are in direct contact with the expert leading their care.
- Clarity on what to look out for themselves can alleviate anxiety – not just noticeable changes, but other ways to keep a check on stability.

RESULTS

Twenty-six patients were included in the study: 18 participating across three focus groups, and eight via one-to-one interviews (Table 1). Seven of the participants were from higher-risk ethnic backgrounds for glaucoma. **Six themes emerged as the most important aspects to be addressed by patients:** Accurate, targeted testing; Swift diagnosis; Options/reassurance; Joined up care; Ownership; Patient friendly information.

HIGHER-RISK GROUPS – ADDITIONAL INSIGHTS

Those at higher risk are not always aware of this elevated risk; even when they are aware, there is a disconnect between their theoretical risk, and their own sense of personal risk. Patients from high-risk ethnic backgrounds and lower socio-economic groups highlighted the need for:

- **Targeted screening and awareness campaigns.**
- **Specific and relevant information to improve engagement and self-advocacy.**
- **Enhanced training for front-line healthcare professionals (e.g., opticians) to ensure targeted screening is undertaken.**

CONCLUSION

This study highlights patients' expectations for their glaucoma care and provides actionable insights to improve their future experiences. Key priorities include:

- **Building patient confidence through accurate testing and clear communication.**
- **Empowering patients with ownership and self-advocacy tools.**
- **Ensuring joined-up care and targeted support for high-risk groups.**

The data gathered can be deployed to build patients' confidence in the healthcare system and support patient engagement. These principles of "what good care looks like" for patients could be used to inform the future design and implementation of glaucoma services to help patients feel a stronger sense of agency; a sense of control, autonomy, and active participation in managing their long-term condition.

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Conflicts of interest

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